Health Information Technology Advisory Committee
Office of the National Coordinator for Health Information Technology

Information Blocking (IB) Workgroup 1

Transcript
March 28, 2019
Virtual Meeting

SPEAKERS

Name	Organization	Title
Michael Adcock	Individual	Co-Chair
Andrew Truscott	Accenture	Co-Chair
Cynthia A. Fisher	WaterRev LLC	Member
Valerie Grey	New York eHealth Collaborative	Member
Anil K. Jain	IBM Watson Health	Member
John Kansky	Indiana Health Information Exchange	Member
Steven Lane	Sutter Health	Member
Arien Malec	Change Healthcare	Member
Denni McColm	Citizens Memorial Healthcare	Member
Aaron Miri	The University of Texas at Austin, Dell Medical School and UT Health Austin	Member
Sasha TerMaat	Epic	Member
Lauren Thompson	DoD/VA Interagency Program Office	Member
Sheryl Turney	Anthem Blue Cross Blue Shield	Member
Denise Webb	Individual	Member
Mark Knee	Office of the National Coordinator	Staff Lead
Penelope Hughes	Office of the National Coordinator	Staff Lead

Operator

All lines are now bridged.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Good afternoon, everyone. Apologies for the delay in getting started. Welcome to the workgroup one, information blocking taskforce. Andy Truscott?

Andrew Truscott - Accenture - Co-Chair

Present.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Michael Adcock? Sheryl Turney?

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Present.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

John Kansky? Denni McColm? Cynthia Fisher?

Cynthia A. Fisher - WaterRev LLC - Member

Yes, I am here.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

All right. Mark, I will hand it over to you.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

Hey, everyone. Thanks for calling in again. I think we made really good headway yesterday. I wanted to just kind of circle back before we jump into HIE and HIN since Andy is on the call, a few points that we talked about and also, one thing I missed that I want to make sure we're clear on. I have my screen pulled up. If you all have access to it, you can see the EHI definition up on the screen.

We landed on our – not really changing much from the ONC-proposed definition of EHI except including as-defined in HIPAA right here regarding EPHI. But I've overlooked – it was not my intention – that there was one other proposed change to the definition that I believe Andy and maybe Michael had put in there to make after payments right here, a parenthetical (s) to, I guess, indicate multiple payments. Andy, do you want to speak to that change and why you think it's necessary?

Andrew Truscott - Accenture - Co-Chair
Only because you can have more than one payment from more than one source. You wouldn't want to inadvertently introduce a dependency on it being singular and only address when all of them – it just kind of was a whole bunch of potential – it could be misinterpreted.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
John just joined.

Andrew Truscott - Accenture - Co-Chair
Hey, John.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
What do others think about that one? Any thoughts?

Andrew Truscott - Accenture - Co-Chair
I must confess. I didn't think was **[inaudible] [00:02:32]**.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member
I'm fine with that change. Sorry, this is Sheryl. I'm fine with that change.

Andrew Truscott - Accenture - Co-Chair
Thank you, Sheryl.

Michael Adcock - Individual - Co-Chair
This is Michael. I think that's fine as well.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
Hey, Michael. Okay. I guess I'll just weigh in – the way I read it was that payment could be plural, but if you all think that's not clear, the adding the parenthetical, you should definitely make that recommendation.

Andrew Truscott - Accenture - Co-Chair
Minor, fine.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
Yeah. Okay. All right. So, if everyone's okay with that, that will be an additional recommendation. The other issue was just the audit issue that we talked about yesterday. I was filling Andy in briefly and I believe summarizing what the group said, but essentially I think everyone felt that audit was really important for patients to know who touched their

records or saw them or had access to them, but we weren't sure if including audit was appropriate in the definition of EHI and maybe we should address it in a different way. Was that accurate, for those who were on the call yesterday?

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

This is Sheryl. That was accurate.

Andrew Truscott - Accenture - Co-Chair

I'm glad that you discussed that. I'm sorry I wasn't here to be part of that conversation. What was the other way that we thought it could be addressed?

John Kansky - Indiana Health Information Exchange - Member

This is John. I think my view was that audit isn't information that's perceived as – the information that's being blocked, it causes a problem to patients and the healthcare system. Audit information being blocked isn't the problem, point number one. Point number two is that HIPAA grants patients right to know where their information has been used and disclosed outside treatment payment and operations and that that right exists and largely granted patients a reasonable right to that access today.

Andrew Truscott - Accenture - Co-Chair

Okay. The only reason I brought it up is because my inboxes lit up in the last week, probably, with various people and groups saying, "You guys have completely got it all wrong. You've forgotten all about audit information." Then when you peel back the onion, it's actually not full audit trails. It's just, "Who has accessed my information?" Does HIPAA give us what is required there?

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

So, wait a second. If you recall – I'm not an attorney and don't play one on TV – there was a HIPAA expansion maybe five years ago. One of those things that was contemplated that was deemed – I don't know at what level it was deemed – impractical or unhelpful to broaden the patient's right to – right now, they have a right to an accounting of disclosure for anything that's outside treatment payment and operations and it was considered to expand that right to include disclosures for treatment payment and operations.

I think that would be probably literally 500, 1,000, or 50,000 times as much information. I think that was realized to be potentially impractical for implementation.

Andrew Truscott - Accenture - Co-Chair

Okay.

Cynthia A. Fisher - WaterRev LLC - Member

I thought that yesterday we had spoken about how important it is in Google or whatever that you could click on the provenance of where your information has been used and also where it has been brokered. So, I thought that it's like a historical trail that could be a click for the patients to have access to. Right now, patients aren't getting access to their information readily available. Many don't even have the right to see where it's going. I don't even know of patients knowing how to go approach getting access to where it's going.

So, I think what we're trying to do is open this up, open the pipeline that patients have ease of access to both their information and their provenance.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

Andy, one thing that I'm just thinking about is whether you think that it might implicitly be already included in our definition. Without calling out, the definition is quite broad.

Andrew Truscott - Accenture - Co-Chair

I don't think so, Mark. The current way the definition is phrased is it's about health conditions and how that healthcare is provided and about payments around that healthcare. It's not saying, "And who has accessed that information?" This is very much around defining what EHI is as opposed to when we undertake the verb of information sharing, whether the details of that sharing counts as EHI.

Does that make sense? There's a whole set of rules around information blocking. It's about preventing blocking and enabling sharing. Then it's kind of like the metadata around that information sharing. Should that be considered to be EHI even in itself? I think that's what we're saying – not the full audit trail because that would be a nightmare.

Let's be fair – keeping track of where information has been shared to or who has accessed Andy's information, that's not trivial. I'm not saying it's impossible. I don't think it's **[inaudible] [00:09:06]**. We pass consent directives and all that kind of stuff around all the time. I don't think this is overly burdensome. I definitely think it's feasible. I'm just not sure the one place to do it is inside EHI.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Yeah. This is Sheryl. I don't think it belongs in EHI. I think EHI needs to be specific to the definition we've already defined.

Andrew Truscott - Accenture - Co-Chair

[Inaudible] care, yes.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

If there needs to be additional qualification that data around that – in the USCDI taskforce, we did talk about the fact that we need data provenance and we got specific guidance from ONC to make it simpler because if we try to provide that audit trail type of thing that you're talking about, it would never get implemented. That was their specific guidance.

Andrew Truscott - Accenture - Co-Chair

To avoid a doubt, I'm not saying implementing audit trails. I think implementing full audit trail, **[inaudible]**, that would be just a nightmare. That is overly burdensome and vastly ineffective to what we're trying to make happen here. I don't want to confuse this necessarily with provenance.

Provenance is a lineage of data, where it's come from – who created it, the context, etc. That makes perfect sense. I see why USCDI is touching upon that. What I'm talking about is where information has been shared. As a patient, it sounds like people are saying HIPAA lets you do this, but as a patient, I should be able to know where my information is being shared to.

Cynthia A. Fisher - WaterRev LLC - Member

Andy, I agree with Sheryl. I think the health definition is fine. I think there is a separate question in the rulemaking that Mark, you might be able to – it's something about the export and patients also having control of choice of where they want their data shared. I think it talks about in the technology development side of that sharing, there's a separate question outside –

Andrew Truscott - Accenture - Co-Chair

I'm actually glad to think maybe we should just say, "ONC, we think you should consider an additional class of data that concerns the sharing."

Cynthia A. Fisher - WaterRev LLC - Member

I just don't want to make it more complicated than it is. The health information, the provenance, and the audit trail, I believe, was included in the request for proposal elsewhere. Are we making **[inaudible] [00:12:00]** out of this molehill?

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

I think what Cynthia's talking about is the certification criterion for B10, which is data export. Sheryl, in your workgroup, that's being discussed or your taskforce?

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Yes. so, I agree with what Cynthia just said too. I agree that we need to provide the data and it would be more helpful to be provided electronically. I just don't think it belongs in the health information exchange definition. That's all.

Andrew Truscott - Accenture - Co-Chair

I agree with you on that one, Sheryl. I don't think it belongs in EHI. That's why I'm saying do we actually just want to go back and say to ONC you probably need to come up with an additional class of data definition for these things that don't belong inside EHI but need to be handled.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Exactly.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

So, I might raise the question for the group would that be in the context of information blocking or would it be more as we're talking about in the USCDI or B10 context?

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

I think it should be in information blocking because at the end of the day, we want to ensure that people are not blocking the access to information. I think that's the point Cynthia was trying to make previously is that if people ask for the data, they have a right to it and they should be provided that data.

Cynthia A. Fisher - WaterRev LLC - Member

I think this is where one of the things I think we want to be is that the data should be provided. People don't ask because they don't know what they can ask for. I think the one thing is we want to make sure there's transparency and there's openness for patients to have access to all of this information. They don't necessarily have to ask for it. It's readily available that they could click on the provenance or they could look at pricing.

They could look at payment past, present, and future that they could manage their health because it's there for them through their open API or through their verified repository. Patients have the ability to get it. It's sort of like all the information in my bank account is there. My bank doesn't hide the transaction data from me. I see it visibly.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Right. But there are some problems that have to be solved before this can be automated, just so this group knows. Today, we don't have a standard way of capturing the organization-level source ID or the date and timestamp in the records so that we can tell you where the data went. So, we have to solve that problem in another workgroup, but then it needs to come together as the full rule. So, it's well and good to put it there, but there is going to need to be some time for implementation because today, there's no standard for capturing any of it. So, that makes it problematic to make it available in an automated fashion.

Cynthia A. Fisher - WaterRev LLC - Member

I think what's hard in some of these things is the entanglement on standards that aren't necessarily because if you want to get a committee of 20 to do anything, it can take another ten years, but a lot of these things are automatic and they're built into the software and can be timestamped. We just want to be really practical and not create unnecessary hurdles. The processes themselves sometimes feel like information blocking, at least from the patient's standpoint when we look at the world in which we live technologically.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

I just want to acknowledge John has had his hand in the queue.

Andrew Truscott - Accenture - Co-Chair

Sorry, John. You should have just interrupted.

John Kansky - Indiana Health Information Exchange - Member

I was trying. Related to the points that are being made, I just want to add – this may land with a thud, but an implementation question – we're suggesting that a patient can go to whether it's a large IDN or a solo practice and say, "I want to know where every lab order ever went, every prescription ever went, every claim ever went, every claim attachment ever went, every electronic fax you ever sent about me, I want to know where it went. I'll wait." How is that possibly implementable?

Andrew Truscott - Accenture - Co-Chair

We need to discuss this one out, John. This isn't for this group to do it. I think we've already established that because it's not **[inaudible] [00:16:56]**, but I think it should be discussed. I'll be delighted to sit down with whoever decides to then take that on forward. But the fact is, knowing where data has gone to is kind of implicit in what 21st Century Cures was trying to say. You will share that data and you'll make sure parents are aware of what you're doing with that data. Patients are aware of what you're doing with their data. So, it is implicit.

John Kansky - Indiana Health Information Exchange - Member

So, Andy, just to that point, one really problematic aspect of the proposal, if you're not putting in the definition of EHI, Congress said access exchange or use of electronic health information. It would be very problematic in my opinion to include it in the information blocking provision because that wasn't – Congress was pretty specific that we're talking about EHI here.

Andrew Truscott - Accenture - Co-Chair

Okay. So, you're saying because we're not including this inside of EHI, we couldn't – okay. That has nothing to do with **[inaudible]**. That has to do with the definition, right?

John Kansky - Indiana Health Information Exchange - Member

It had to do with as far as ONC's ability to implement the recommendations, I can see that has potential.

Andrew Truscott - Accenture - Co-Chair

Yeah.

Cynthia A. Fisher - WaterRev LLC - Member

Are we making something unnecessarily complicated? Mark, can you clearly just state where we are and then we move forward? I think we've just been in circles.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

Yeah. I think we can definitely move on and come back to this one. So, the issue is, I think, Andy and others feel that audit is something – Andy was clear in what he means a patient being able to see who had touched their records.

Andrew Truscott - Accenture - Co-Chair

No, who has shared it and where has it been shared to – not who's touched on it because that makes no sense. I don't know. MD Anderson has got a bunch of records and now Memorial Hermann has **[inaudible]**. So, that kind of level seems reasonable.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

Okay. So, yeah.

Cynthia A. Fisher - WaterRev LLC - Member

Are we also looking to empower the patient that they can deny use for marketing and market research. **[Inaudible] [00:19:32]** can have that opportunity to control their secured health information.

Andrew Truscott - Accenture - Co-Chair

I actually think we should be going there eventually. I think definitely control how my information might be used in marketing purposes, etc. Let's look at Australia as a counter point here. So, the Australian personally controlled electronic health record – a patient who has a PCHR can go and define with a very fine degree of granularity where they can sense their information being shared. They can also see with a very fine degree of granularity whose accessed their PCHR. It doesn't seem unreasonable that our patients in the US have the same expectation of being able to control how their information is used or is it? Cynthia?

Cynthia A. Fisher - WaterRev LLC - Member

I didn't know you were looking for a response. Sorry.

Andrew Truscott - Accenture - Co-Chair

I kind of am. Is that what you're thinking?

Cynthia A. Fisher - WaterRev LLC - Member

Yeah. I guess.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

So, Andy, do you want to maybe put a flag in this one to come back to or how do you want to handle this?

Andrew Truscott - Accenture - Co-Chair

Well, I think we'll raise this one just as a note to ONC saying we need to look at this. You guys can't look at anything unless we raise it.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

Right. I think you can definitely make a recommendation and say we don't want this included in the definition of EHI and we understand that would mean that it probably wouldn't be covered for information blocking, but this is an important issue that needs to be addressed in some capacity or something like that.

Cynthia A. Fisher - WaterRev LLC - Member

But wait a minute – did we say that it wouldn't be included? I thought Sheryl wanted it as part of information blocking. I think it's inclusive of the patient's record. Information blocking, I guess, reads back to the EHI definition and the question mark, what I'm hearing is, "Is the provenance considered part of the health information and the health information of showing where their information is being distributed?" Is that the question?

Andrew Truscott - Accenture - Co-Chair

Let's be clear on the language there, Cynthia, because provenance we normally use specifically to say who created the data and the context in which it was created. We don't use it to describe who's accessed it. I think provenance-wise, that probably should be EHI and that's probably why USCDI is going through it. But here, we're talking about kind of the information sharing data. Who has it been shared with? How has it been shared?

John Kansky - Indiana Health Information Exchange - Member

So, Cynthia, I think you got the issue right. All I'm saying is – to interject into the conversation – is that in Cures, the definition of information blocking talks about interfering with, preventing, or materially discouraging access, exchange, or use of electronic health information.

So, if you all wanted audits, however you define it, to be something that would be looked at under the information blocking provision and enforcement, all I was saying is that the way I read that, it would need to be in the definition of EHI. Otherwise, it seems like it might be, based on what Congress said, outside the scope of the information blocking provision.

Cynthia A. Fisher - WaterRev LLC - Member

Yeah. I think the thing is you want that to be available and then in the same sense, you want the data access most importantly to be what the patient needs to get the best of care. The more important thing is for the patient to get access to their information and get access to pricing and payment. I'm fine with the EHI as it is.

I think the thing is, maybe audit is part of the USCDI. It's something that should be – if HIPAA has had it as a requirement all along, that requirement stays and it becomes part of the electronic health record that's identifiable because that is identifiable to the patient. So, I guess if you really read the EHI definition, it probably is included because of patient-identifiable information.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Actually, I don’t think it is because the information about where data is shared has no identifiable data. I know we as a payer – and I don't know how other payers do it – actually have a database that we maintain. We identify when that data is shared externally. We don’t identify all the internal data shares.

So, if we had vendors or others that are doing work on our behalf, that would not be captured in that capacity, but any external request for mandates and other things would be because we need to have that data available to provide. It isn’t electronic. So, we can’t provide it electronically to the patient or the member, but we provide it through a paper means today.

But I don’t think it should be included as part of EHI because that’s basically expanding on the definition in a way that we can’t – I would agree, let USCDI deal with it because the audit data would then go through the promotion model that we’ve already participated in last year and be identified as a data element and at the appropriate time, it could be further scoped out, defined as terms of what that means at a time when potentially that data is there.

Andy, what you might have missed in the meeting that we had yesterday was that there was apparent, I think, misunderstanding that today, payers and others would have that breadcrumb trail that Google has that tells you where the data has gone.

Andrew Truscott - Accenture - Co-Chair

We don’t have it. I know we don’t.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

We don’t have it. Our systems are not set up that way. That would be a complete change of how we work and that will take some years to accomplish.

Andrew Truscott - Accenture - Co-Chair

I know you don’t have it. I’m not sure it’s complete change. I think **[inaudible] [00:27:06]**. Because the information sharing itself is an auditable activity, it actually wouldn’t be that hard to claim **[inaudible]** audit trail, technically. But that’s kind of by the by. I agree with you guys that full audit trails as a definition of EHI just doesn’t seem to hold water.

What I’ve been toying with as we’ve been talking is the idea – if we say EHI means one EPI or EPHI, as defined in HIPAA, two, any other information that identifies individuals for healthcare purposes. I’m actually wondering whether it might be feasible to add a three. I’ve got a draft on screen there that says three – information concerning patient consent to information sharing and information as to who has access to that patient information. That’s it – keep it that vanilla.

We’ll just call it patient consent to information sharing. I’m not so naïve as to achieve tacit agreement. What do you guys think? Do you guys think this is a step too far?

John Kansky - Indiana Health Information Exchange - Member

Andy, I’m just trying to figure out what my opinion is. So, give me a minute.

Andrew Truscott - Accenture - Co-Chair
That’s okay.

Cynthia A. Fisher - WaterRev LLC - Member
Same here.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
Andy, while they’re thinking about how they feel, can you just frame it one more time, like how the recommendation would work? I just want to make sure I understand.

Andrew Truscott - Accenture - Co-Chair
What do you mean how it would work, technically?

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
So, I see what you have written up there. Can you just restate it? Maybe that would be helpful for me. I’m not sure I’m totally following.

Andrew Truscott - Accenture - Co-Chair
You want me to play Jack **[inaudible] [00:30:07]**? Okay.

Cynthia A. Fisher - WaterRev LLC - Member
Andy, I think we have trouble with your English sometimes. I’m being honest. I’m looking at three and three under, “May cause consternation amongst the vendor community.” I mean…

Andrew Truscott - Accenture - Co-Chair
That’s not –

Cynthia A. Fisher - WaterRev LLC - Member
That’s an opinion. It’s sort of an awkward thing to say within rulemaking.

Andrew Truscott - Accenture - Co-Chair
No, it’s not in rulemaking. That’s just my note to us. I’ll put that in the notes. Sorry.

John Kansky - Indiana Health Information Exchange - Member
Andy’s the only one that speaks English.

Andrew Truscott - Accenture - Co-Chair
That’s now a matter of public record, John.

Cynthia A. Fisher - WaterRev LLC - Member
I think we want to – I don't know what you're saying. As I read your sentence in three, it doesn't quite make sense to me.

Andrew Truscott - Accenture - Co-Chair
Okay.

Cynthia A. Fisher - WaterRev LLC - Member
Are you saying that a patient wants to be informed for their patient sharing and wants to be in control of access also and have –

Andrew Truscott - Accenture - Co-Chair
Okay. I don't think this is where we put this thing about control.

Cynthia A. Fisher - WaterRev LLC - Member
Then the second part is –

Andrew Truscott - Accenture - Co-Chair
This isn't the right place to talk about control.

Cynthia A. Fisher - WaterRev LLC - Member
There was the definition of the audit and then there was the provenance. There was the audit of information, where the information is going and consent to and then the provenance is a separate USCDI. I guess I **[inaudible] [00:32:15]** understand – this says relevant statutory terms and provisions. So, I'm just trying to understand what the question is and what our answers are.

Andrew Truscott - Accenture - Co-Chair
Okay. All I'm suggesting is that like it or not, I'm asking the group as to whether the EHI definition, to Sheryl's point, should be updated to include that item three and item four. So, item three is the patient consent. So, when a patient makes a consent directive, should we treat the consent directive as electronic health information?

And then separately, should we treat information about where that electronic health information is being shared – should we also treat that as electronic health information given that EHI is the definition of the information world, which we can talk about? There is no listed mandate, from what Mark's been saying to us, that allows ONC to consider other classes of data.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
Within information blocking is what I'm saying. Curious language.

Andrew Truscott - Accenture - Co-Chair

So, if we want to say look, we don't want to block patient consent information from being shared and we want to make sure access to patient information logs are not logs. We need to build those inside that definition. Is that correct, Mark?

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
I guess I'm not trying to provide any kind of guidance on this. All I'm saying is that in Cures, the way that information blocking is defined is as an interference with the access, exchange, or use of electronic health information. As far as I'm reading it, the information that we would look at for information blocking plans would be EHI as we define it.

Cynthia A. Fisher - WaterRev LLC - Member
I agree with that. I think patient access – what Mark just said was very clear.

Andrew Truscott - Accenture - Co-Chair
No, but that hasn't answered the question. The question is look, if you guys think that we want to make sure that patient consent decisions are not blocked from sharing, then we should include it. If we think we want to make sure that information about who has access and shared patient information is not blocked from being exchanged and shared around, then we should include it. If we are happy for patient consent information not to be shared and if we're happy for access information about patient records not to be shared, then we should exclude it.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
Andy, two things – one is I hear you – who typed No. 4? It's not what you said.

Andrew Truscott - Accenture - Co-Chair
I did, but you can rewrite it. I can't type and talk at the same time.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead
I think it's an important distinction that you keep saying who it's been shared with and who it's been accessed by is a completely different problem. So, let's stick to shared, which is what you keep saying. So, that's point No. 1. Point No. 2 is I don't completely concur with the way that you characterized it as if we want it to be not blocked, we better name and if we are okay with it being blocked, then we don't have to name it.

Here's the conundrum I find myself stuck in. Having lived through HIPAA, if you have a definition that doesn't parse out the 56 specific examples or 24 specific examples of what you mean in that definition, the world of organizations who are trying to comply and their consultants and their lawyers will set about the task of trying to figure that out and ONC will issue guidance documents and the world, just as it did with HIPAA, will figure out what we mean by that.

Alternatively, we can try to put in those 24 or 56 things that it means – and I think that's essentially what we've been spending some time on these calls trying to do – what I'm starting to sense is that three and four are just examples of the 24 things that we mean when we say that broad definition above and does listing three and four specifically serve to clarify or confuse because we haven't listed the other 22. Does that make sense?

Andrew Truscott - Accenture - Co-Chair

Yeah. I hear what you're saying. Part of this is my responding also to some of the focus that's been given on this from outside. My reading of two is that two is absolutely focused upon the acts of providing healthcare. The three and four drafting are not included in the acts of providing healthcare. They're specific around the access to information. That's how I read it. I could appreciate others might think differently.

John Kansky - Indiana Health Information Exchange - Member

I don't know how much detail the preamble goes into around what is meant by the definition, but I can certainly see helpful – so, it's easy to say and really hard to do. What I've been trying to nudge towards is a clear definition that's broad with as few confusing words in it as possible in the actual regulation and then ample preamble that says, "So, when we have the definition of EHI, we absolutely mean this. We don't mean this. Here are some examples of what we mean. Here are some examples of what we don't," so that the community of organizations trying to comply with the law have the best chance of understanding it.

Andrew Truscott - Accenture - Co-Chair

That's fine. Hang on a second. John, do you think this is – we should just put this in the preamble, but we should make sure it's called out.

Mark Knee – Office of the National Coordinator for Health Information Technology - Staff Lead

Andy, I'm just saying I have to jump off right now. I have something else I need to get to right now.

Andrew Truscott - Accenture - Co-Chair

Okay. Thanks. So, John, so you actually think we should talk about this? We should just put it in the preamble?

John Kansky - Indiana Health Information Exchange - Member

Yeah. I think that's my opinion. I'm dead wrong if you think the definition as written clearly leaves out this stuff. I haven't convinced myself that – the definition is broad and furry. So, the world is going to have to interpret the definition in its broadness and its furriness. So, if you think that these things or the group feel these things are clearly outside the definition, then we have no choice. It's back to what you suggested. If we don't call them out as in, then they're not subject to information blocking. What I guess I'm assuming is that the definition is broad enough that I think the world may end up interpreting them as is.

Andrew Truscott - Accenture - Co-Chair

My interpretation of the definition as it currently stands is it's specifically about past, present, or future health or condition. It's very, very focused upon – you've got the HIPAA definition and you've got the **[inaudible] [00:40:39]** regulation and that seems to be very, very much based upon the current disposition of the patient or the past, present, and future disposition of the patient, and then the payments for that healthcare.

It absolutely is my interpretation. I'll be interested how you could interpret what is, albeit, a very broad definition, to actually include consent for information sharing and information about where information is being shared to. I cannot see how that could possibly be interpreted in the current drafting of two.

John Kansky - Indiana Health Information Exchange - Member

I guess I've realized I've been acting under a somewhat unexpressed philosophy that is not going to have full agreement with the rest of the group here. I'm of the opinion that we want a regulation that – I want patients and I want providers to be able to get access to the data that they can't today that most people think about when they think of information blocking.

I don't know if I'm articulating this very well, but gosh darn it, if you want information about the care you receive from the provider, you should be able to get it and if another provider needs it because they're caring for you, they should be able to get it. If that leads to price transparency or that – that's what we want. I just feel like we're really just trying to sweep the last little bit of dust out of every corner.

I think every 1% further we reach increases 10% of the challenge and cost of the regulation. I know that's not the question we're being asked. So, I'm just acknowledging that that's the lens **[inaudible] [00:42:51]**.

Andrew Truscott - Accenture - Co-Chair

Implication.

John Kansky - Indiana Health Information Exchange - Member

Yes, thank you.

Andrew Truscott - Accenture - Co-Chair

I'm not disagreeing with any of that. My view here is I'm just trying to future-proof this. Having watched these types of regulations get put in place in other jurisdictions and seen how in two or three years' time, there becomes a bonfire around, "Well, okay, I didn't know that patient hadn't made that consent direction over there." That wasn't shared with me. I can see their information, but I couldn't have received a consent directive. That wasn't include with it.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

I'm not sure I followed what you just said, Andy. I apologize. I don't know. It looks like it's time for public comment. Maybe we should do that and come back to this.

Andrew Truscott - Accenture - Co-Chair

[Inaudible] on to public comment for me. Okay. Yeah. Let's go to public comment.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Sure. Operator, can we open the line.

Operator

If you'd like to make a public comment, please press star-one on your telephone keypad. A confirmation tone will indicate your line is in the queue. You may press star-two if you'd like to remove your comment from the queue. For participants using speaker equipment, it may be necessary to pick up your handset before pressing the star key.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

And do we have any comments in the queue?

Operator

None at this time.

Andrew Truscott - Accenture - Co-Chair

This is a particular subject matter that would be great to have public comment on.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Yeah. Maybe we'll leave the phone number up for the next few minutes and then we can come back to see if we have any more comments.

Andrew Truscott - Accenture - Co-Chair

Okay. So, Sheryl, what I was trying to say there is the way it's currently drafted, I could see very clearly that information should be shared about healthcare. Gosh darn it, as John said, we'll enable that to happen. Got that. What isn't clear to me is that patient consent directives around that information are included, nor that patients will be able to see where their information has been shared in a transparent way.

Looking at lessons learned from elsewhere, where there has been a focus upon the enabling and for sharing and the gap has come to light later is actually there's a need for better insights as to how that information is being shared and controls upon it. Control not in preventing sharing, but just to respect the wishes of patients and how they want their information to be shared.

John Kansky - Indiana Health Information Exchange - Member

Andy, in the example that you're thinking of, is it the sharing or treatment payment or operations that is in question that patients end up wanting to know?

Andrew Truscott - Accenture - Co-Chair

It's generally for treatment, actually.

John Kansky - Indiana Health Information Exchange - Member

It is for treatment?

Andrew Truscott - Accenture - Co-Chair

Yeah. It's for treatment. Patients want to know, "Who's actually had my information shared to them?" You hit a good point there, which is I should know where I'm receiving treatment.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

I don't disagree, Andy, but I'm looking at it punting it down the road. We have implemented this rule now. All of a sudden, we're opening the gates to many others to use the data for other purposes that may contain identifiable data.

So, per John Kansky's note earlier, how can that possibly be managed. We participate in an HIE, like we give data to Indiana so that we can get clinical records back from them on the patients and be able to do care management. They may share that data with I don't know how many people for purposes they've defined that are appropriate. We wouldn't know who all those people are that are getting that data.

Andrew Truscott - Accenture - Co-Chair

Absolutely not. You were just saying you had shared it with Indiana and that's it. You could only ever say, "We've shared it with Indiana health insurance."

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Right. What I'm saying is I do think this needs to be thought out more. In the discussions that we had yesterday, which I know you weren't part of, I used the example of a vendor and this is a real vendor whose name will be left out, but they basically get data on behalf of some of our employer groups and then they create a separate database from identifiable data with the PHI stripped out, but then that database is sold to hundreds of people.

So, if this is something that comes to fruition, what are their responsibilities and accountabilities related to that data? They're not a vendor of ours, so, we can't limit what they do. At the end of the day, I have no idea who the hundreds of thousands of people are they've sold that data to. So, there are some issues that need to be addressed in a bigger forum, I believe.

I agree with the comment – I'm sorry if I forgot your name, whoever said it – but I think this really needs to focus on the problem we're trying to solve right here, which is getting patients more easy electronic access to their data. I think this is a problem that really is going to require some greater discussion to ensure that it actually achieves what is expected. I believe the responsibilities will be on not only covered entities but non-covered entities.

As you know, HIPAA only discusses covered entities. Here, we're trying to broaden it to certified responsibilities of certified developers. So, what's their responsibility related to this? Essentially, it could mean they need to provide information on all of the uses of that data that basically could be used in even a commercial database that the patient is unaware of.

Andrew Truscott - Accenture - Co-Chair

I agree. Okay. I'm not going to **[inaudible] [00:49:36]**… So, I'll just say we recommend that ONC considers potentially including these types of data and it might even be possible to take it outside of these regulations.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Your headset or whatever you're talking on is sort of muffling your voice. So, it's hard to understand you.

Andrew Truscott - Accenture - Co-Chair

I'm saying take it to ONC, say, "You need to think about this. It might not be the right place to include it. Have a think about it," basically. Does that work for you, Sheryl?

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Yeah. I think that's what I mean.

Andrew Truscott - Accenture - Co-Chair

Okay. Have we got any public comment.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Operator, any comments?

Operator

There are none in the queue.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Okay. Thanks.

Andrew Truscott - Accenture - Co-Chair

Okay. So, it's kind of homework – before we meet again, can everyone go through the recommendations across these and make sure that we're happy with them? If you're not happy with them, add in drafting that you would prefer to have.

John Kansky - Indiana Health Information Exchange - Member

Yeah.

Cynthia A. Fisher - WaterRev LLC - Member

Andy, it's really hard to hear you clearly when you speak. It's very muffled, FYI, however your phone is.

Andrew Truscott - Accenture - Co-Chair

My phone is actually –

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Yeah, that's better, Andy.

Andrew Truscott - Accenture - Co-Chair

Is that better? Okay. Fine. I'm asking everyone to do homework and saying before we meet again, can you go through the recommendations as they're currently drafted and either note you're in agreement or note that you want some changes so we can get those changes and we get these to at least a state that we can pass them to the board or taskforce on the 5th of April.

Cynthia A. Fisher - WaterRev LLC - Member

I have a question – is there any disclosure anywhere in the ONC ruling that patients need to be informed? If we're not going to have the audit trail or we're not going to have the audit trail and we're not going to have the provenance or whatever, is there a place that patients need to be aware of how much their information is brokered behind the scenes?

I think there's a big vast void of ignorance of how information is aggregated, de-identified, then re-identified and brokered through many different players behind the scenes. I was wondering if maybe ONC can tell us or maybe ONC is off the line, but is there a disclosure that just doesn't say that your information is shared for your insurer in potential research? Is there something that's more overt to patients in the rulemaking?

Andrew Truscott - Accenture - Co-Chair

John Rancourt? We're calling on you at this point.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

He had to leave. He put it in the chat, Andy. I think we need that, Cynthia. I will tell you I've been working with these state APCDs for years and they basically sell everybody's data that's collected in every state and they provide no notices to anyone that's being sold for a whole variety of purposes.

Andrew Truscott - Accenture - Co-Chair

John's actually just sent in, "I'm on, but I don't know the specific answer." He'll get that and bring it to the next call. Okay.

John Kansky - Indiana Health Information Exchange - Member

I’ll comment. This is John Kansky, not Rancourt. I agree with Cynthia and Sheryl that that’s a problem. I think it’s interesting that if that were a covered entity, the patient has that right to request – nobody ever does it, hardly ever – for un-accounting of disclosure. But as soon as that information is disclosed to not a covered entity, all bets are off.

Andrew Truscott - Accenture - Co-Chair

Yeah. I think the point that was made is even if they are a covered entity, patients aren’t aware, necessarily, they have to go and request because they’re not aware they got that information and also, if they’re not a covered entity, all bets are off.

John Kansky - Indiana Health Information Exchange - Member

Got it.

Cynthia A. Fisher - WaterRev LLC - Member

What is the acronym for the European privacy – the GDPR or something like that –

Andrew Truscott - Accenture - Co-Chair

GDPR.

Cynthia A. Fisher - WaterRev LLC - Member

GDPR.

Andrew Truscott - Accenture - Co-Chair

Great piece of legislation, yeah.

Cynthia A. Fisher - WaterRev LLC - Member

So, as we look at where Europe has come ahead of this, wouldn’t that also be in preparation for patient full disclosure? I think we’re just moving toward patient transparency, full disclosure. I do think it’s worth a discussion in this rulemaking if information blocking is there to give patients access. So, there’s a lot of access behind the scenes of the patient data except for the patients themselves to control and manage and choose their healthcare and their care of their wealth as well.

Andrew Truscott - Accenture - Co-Chair

Okay. In the same way that we are absolutely, as a group, in agreement, the price information should be included in this definition of EHI because in the future, then there will be additional regulation around price transparency that’s going to depend upon it. I need you guys to think very hard about whether we want to make a recommendation here for this kind of information to be included as well in the definition of EHI so that in the future, there can be regulation to enable precisely what Cynthia has just been talking about.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Will do, Andy. When is our homework due? You want it in the Google doc? Just so you know, I have to edit it outside of my company system because it blocks it. I think last time I had trouble because it wouldn't recognize my personal email that's associated with Google. So, let me know if I need to send you that or something.

Andrew Truscott - Accenture - Co-Chair

Okay. If you send me anything that you need printing, I will commit to getting that in for you. That's fine. When is our next workgroup meeting? Can someone from ONC chip in and tell us that?

John Kansky - Indiana Health Information Exchange - Member

Next Wednesday?

Andrew Truscott - Accenture - Co-Chair

Okay. So, homework due Tuesday morning? Is that feasible?

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

Yes, I think that's good.

Andrew Truscott - Accenture - Co-Chair

Okay. I do feel like a teacher.

Sheryl Turney - Anthem Blue Cross Blue Shield - Member

I have to drop because I'm starting another meeting right now. I apologize.

Andrew Truscott - Accenture - Co-Chair

Me too. Thank you, guys. Take care. Have a good day.

Cynthia A. Fisher - WaterRev LLC - Member

Thank you, everyone.

Lauren Richie – Office of the National Coordinator for Health Information Technology - Designated Federal Officer

Bye, bye.

Andrew Truscott - Accenture - Co-Chair

Bye.